Causes and Attitude of Husbands toward Thalassemic Carrier Screening Test When Their Partners Have Abnormal Screening Tests

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Objective: *To assess the attitude of husbands toward the thalassemic carrier screening test and to explore the causes of non-participation of having a blood test.*
Study design: *Descriptive study.*
Material and Method: *During 2007-2008, 100 husbands of pregnant women with screening-positive test for thalassemia who refused to have blood test were enrolled by voluntariness. They would fill out a structured questionnaire designed for the present study which was divided into 3 parts; (1) participant's personal characteristics (2) their attitudes toward thalassemic carrier screening test with the score ranging from 1-5, and (3) reasons for their refusal of having a blood test.*
Results: *The husbands had a favorable attitude toward testing for thalassemia, with overall mean score and standard deviation of 3.57 and 0.38. Commonly expressed reasons against testing were the self-belief of having a non-affected child and the inconvenience of coming to the hospital.*
Conclusion: *Husbands had a favorable attitude toward test for thalassemia.*

Keywords: *Husband, Thalassemia, Attitude*

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Thalassemia is a common anemic hereditary disease in Thailand. Approximately 12,125 newborns with severe thalassemia are born each year and this leads to socio-economic and medical burden. The screening program in pregnant women is one of the national strategies that aim to prevent new thalassemic births by seeking for couples at risk and providing the appropriate prenatal diagnosis. However, the authors found in our previous study that only 19.4% of husbands whose partners had abnormal thalassemia screening results took part in the screening test[1], thus, identification of the couple at risk could not be done effectively.

Objective

To assess the attitude of husbands toward thalassemic carrier screening test when their pregnant partners have abnormal screening tests and to explore the causes of non-participation in having their blood tested.

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Study design

This descriptive study was conducted at the antenatal clinic of Phramongkutklao Hospital during 2007-2008. The authors enrolled the husbands of pregnant women with abnormal thalassemic screening results who refused to have screening test for thalassemia.

Material and Method

The present study was approved by the Ethical committee. Pregnant women with the screening-positive test for thalassemia would ask their husbands to come for a blood exam and those husbands who refused to have a blood test were invited to take part in the present study. All had to be eligible to read Thai and willing to participate in the present study. The trained personnel would explain the purpose of the present study and counsel the participants about thalassemia regarding symptoms, inheritance, treatment, prenatal diagnosis as well as the risks and benefits of the procedure. Then, 100 participants who were recruited in the present study would fill out a structured questionnaire by themselves.

The questionnaire composed of the potential questions which were generated after review of relevant literature and existing questionnaires[2]. During the developmental process, the authors also asked 2 other staff to review the statements in order to ascertain that they were comprehensible. This self-administered questionnaire was divided into 3 parts; the first part collected information on the participant's personal characteristics, the second part assessed their attitudes toward thalassemic carrier screening test, and the last part elicited the reasons for their refusal of having the blood test. In part 2, participants were asked to reply on a five point Likert scale ranging from "highly disagree" to "highly agree", whereas, in part 3, they would choose either "yes" or "no" for each question.

Statistical analysis

The data were entered into a SPSS database (version 15.0). Demographic data and causes of the refusal of having blood test would be described as percentage while attitudes would be presented as mean score ranging from 1 to 5. For favorable statements, the higher score represented substantial attitude and vice versa for unfavorable statement. Correlation between personal characteristics and attitudes were analyzed using Chi-square test and $p < 0.05$ was interpreted as significant.

Results

The characteristics of participants are shown in Table 1. Mean age of the participants was 29.94 years. Three-fourths (74%) had got education equal or lower than high school level. The majority were laborers (52%), had the income of 5,000-10,000 baht/month (49%), and more than half of them had health insurance.

Table 2 represents the husband's attitudes toward screening test for thalassemia. Among 9 items, item 1, 2, 3, 6, 9 evaluated cognitive components, item 4, 5, 7 explored affective components, and only item 8 assessed behavioral component of attitude. Each item mean score ranged from 2.87 to 4.17, with overall mean score and standard deviation of 3.57 and 0.38, respectively. The result indicated that the husbands had a favorable attitude toward testing for thalassemia with a notable acceptance that the test was beneficial to them and their families in 83/100 and 93/100 participants, consecutively. About half were not sure and/or disagreed that they obtained adequate information about the disease, whether they understood it clearly, or they clearly realized the possibility of having an affected child. Forty per cent were not certain whether to continue or terminate the pregnancy if their offspring was affected.

Reasons against screening test are demonstrated in Table 3. A commonly expressed reasons against testing were the self-belief of having non-affected child and the inconvenience of coming to the hospital. Some also had negative response due to their concern about a disclosure of blood result to other persons (17%), high cost of blood test (21%), no advice of having blood test by anyone (20%), as well as a lack of understanding about the disease (27%).

Correlations between attitudes and personal

Table 1. Demographic Data

Character	Number (%) (n = 100)
Age (mean ± SD) (year)	29.94 ± 6.61
Less than 19	5 (5)
20-29	45 (45)
0-39	42 (42)
More than 40	8 (8)
Educational level	
Not educated	2 (2)
Elementary school	19 (19)
Junior high school	21 (21)
Senior high school or vocational certificate	32 (32)
High vocational certificate	17 (17)
Bachelor's degree or higher	9 (9)
Career	
Unemployed	8 (8)
Laborer	52 (52)
Business owner	29 (29)
Government officer	5 (5)
Others	6 (6)
Health insurance	
Pay by yourself	35 (35)
Universal health insurance	23 (23)
Social securities	30 (30)
Government	7 (7)
Others	5 (5)
Family income (baht/month)	
No income	2 (2)
Less than 5,000	3 (3)
5,000-10,000	49 (49)
More than 10,000-20,000	30 (30)
More than 20,000	16 (16)
Religion	
Buddhist	94 (94)
Muslim	5 (5)
Christian	1 (1)
Having family members with thalassemia	11 (11)

Table 2. Husband's attitudes toward screening test for thalassemia

Statements/Attitude score	Number (%) (n = 100)					Mean score (1-5)*
	Highly disagree	Disagree	Not sure	Agree	Highly agree	
1. You have got enough information about thalassemia from your physician.	1 (1)	11 (11)	35 (35)	47 (47)	6 (6)	3.46
2. You understand distinctly about thalassemia.	1 (1)	7 (7)	40 (40)	45 (45)	7 (7)	3.5
3. You know clearly why you have to screen for thalassemia carrier.	0 (0)	6 (6)	23 (23)	60 (60)	11 (11)	3.76
4. You think that the result of thalassemia carrier screening is beneficial for you.	1 (1)	8 (8)	8 (8)	59 (59)	24 (24)	3.97
5. You think that the result of thalassemia carrier screening is beneficial for your family.	0 (0)	1 (1)	6 (6)	68 (68)	25 (25)	4.17
6. You know clearly the possibility of having a child born with thalassemia.	0 (0)	11 (11)	43 (43)	36 (36)	10 (10)	3.45
7. You would like to know prenatally whether the fetus in utero (your child) is affected by thalassemia.	0 (0)	6 (6)	20 (20)	51 (51)	23 (23)	3.91
8. If the fetus in utero is affected by thalassemia, you would consider termination of pregnancy (abortion).	10 (10)	23 (23)	40 (40)	24 (24)	3 (3)	2.87
9. You think that prenatal diagnosis is not useful in the prevention of thalassemia.	9 (9)	25 (25)	26 (26)	30 (30)	10 (10)	3.07

* Mean score: 1-2.6 = fair attitude (statement 1-8)
= substantial attitude (statement 9)
2.61-3.40 = moderate attitude (statement 1-8)
= moderate attitude (statement 9)
3.41-5.0 = substantial attitude (statement 1-8)
= fair attitude (statement 9)

Table 3. Causes for refusal of having blood test

	Yes	No
1. You are afraid that other people would detest you.	6 (6)	94 (94)
2. You concerned that test results might be disclosed to unauthorized persons/outsiders.	17 (17)	83 (83)
3. You are certain that your child is not affected by thalassemia.	49 (49)	51 (51)
4. The expense for blood test is too expensive.	21 (21)	79 (79)
5. It is inconvenient to come to the hospital.	57 (57)	43 (43)
6. Nobody tells/ recommends you to have blood test.	20 (20)	80 (80)
7. You do not have blood test because you do not understand about information you have been told.	27 (27)	73 (73)

characteristics, were assessed and found significant correlations with occupation. Laborers or business owners tended to have positive attitudes toward the screening test less than those who were unemployed or were a government officer. But there was no significant correlation found between attitudes and other personal characteristics.

Discussion

In Thailand, a national thalassemia prevention program is targeted at 3 severe diseases: Hb Bart's hydrops fetalis, homozygous beta-thalassemia and beta-thalassemia/HbE. A strategy for prevention and control of thalassemia includes population screening for heterozygotes, genetic counseling and prenatal diagnosis with selective abortion of affected pregnancies[3]. It is cost effective to run a universal prenatal screening program in an area where both beta-thalassemia and alpha-thalassemia are prevalent[4]. However, little is known about the acceptability of such screening.

In Obstetrics and Gynecology Department, Phramongkutklao Hospital, the authors use hematocrit, mean corpuscular volume (MCV), and dichlorophenol indol phenol (DCIP) for thalassemia screening in every pregnant woman at the first antenatal visit[1,5,6]. Then, confirmatory diagnosis of alpha and/or beta-thalassemia would be performed on those women with an abnormal screening test. A pregnancy in which both of the couple were carriers is considered at risk and prenatal diagnosis would be offered by the personnel working in Maternal-Fetal medicine unit, and the parent may consider to terminate the pregnancy if the fetus is severely affected.

In order to control thalassemia, not only knowledge about thalassemia has to be strengthened and adequate amounts of expert need to be developed, but also is the participation of the patients and their families. Nevertheless, based on our previous study, only 78 husbands of 380 pregnant women who were carriers had blood tests. The low rate of husband participation was also found in the studies by Greenburg PL, et al[7] and Henneman L, et al[8] which reported only half of the pregnant women who had abnormal screening succeeded in having their husband blood tests.

Screening programs are being determined by professionals, with little consideration being given to the views of recipients. While there are lots of studies looking at attitudes of pregnant women to prenatal testing for thalassemia, little is currently known about their partner's attitudes toward either the introduction of carrier screening for thalassemia, or the termination of any affected fetus. The present study showed that the majority of husbands of screening-positive pregnant women had positive attitudes toward the carrier test, however, they were not corresponding with their actual response of deriving blood test. This finding may be explained in part by the perception that their fetus was not affected by thalassemia. Seeing that three-fourths of participants were not sure or disagreed with termination of pregnancy if the fetus was affected, thus, it was unnecessary for them to know the test results.

Nearly a half of participants addressed that they neither got adequate information from the physician nor understood distinctly about thalassemia. These findings perhaps illustrated both participants' intellectual capacity and communication skills of the counselor. Lack of understanding was claimed as the reason for non-participation in the screening test with the higher proportion among the husbands with lower education level. Therefore, the method or the content of counseling should be adjusted for each individual. The quality of information disseminated by the physicians and other healthcare personnel has to be improved to ensure that the counselee is able to make informed decisions about carrier testing.

The low proportion of those considering termination of a pregnancy for an affected child might reflect the difficulty of dealing with unfamiliar disorder, perceptions of the severity of disease, distrust of accuracy in prenatal diagnosis, or may be influenced by Eastern culture and religious constraints.

Regarding the refraining from having a blood test, 47% expressed the confidence of having a non-affected fetus. This perception may be associated with limited experience of approaching family members with disease[9,10] or 25% empirical risk of having an affected child was negligible for them. Nevertheless, the root of this belief, such as the misunderstanding, inadequate knowledge, should be further explored since the findings would have important implications for future improvement and the success of screening program.

Only 6/100 participants perceived negative consequences of the test results, namely, the fear of being detested by others. This response may relate to the knowledge that thalassemia was not a contagious disease. Unwillingness to let the test results known by other persons was one of the causes for a decline to have a blood test in 17 participants; only 5 of them concurrently expressed the concern to be detested by others while the rest had unclear reasons. Such notions

must be carefully considered and taken into account in planning large-scale testing given that some may have hidden distress that an abnormal blood test would lead to the discrimination in health insurance, work admittance, etc.

There was a statistically significant correlation between attitudes and occupation. Those who were unemployed or government officers had the potential to have more positive attitudes than other career. However, it is unlikely that similar results would have been found if this study had been carried out on larger number of participants.

The drawback of the present study was the possible overestimation of participant's positive attitudes since the authors enrolled only the husbands who came to the hospital and completed the questionnaire voluntarily. This group may have a better attitude toward the screening test comparing to those who did not join in the present study. Another limitation of the current research was that quantitative method using questionnaires appeared to be appropriate for repeated evaluations but the accuracy of ratings could be affected by many methodological factors, including the quality of the instrument in terms of validity, reliability, and sensitivity to changes. For example, some items might have very positive meaning which led most participants expressed in the same way. In addition, the authors tried to limit the number of statements with the intention that participants would consume less time and be more concentrated on questionnaire completion. This may conversely limited the aspects of attitudes to be studied.

Attitude is one of quality outcome indicator of counseling process which could be changed by content of information, counselor, and perception of counselee. Thus, the contribution of this research to the practice with high prevalent population is to apply the finding in the present study for improvement pattern of thalassemia counseling and enhance good attitude toward thalassemia control.

Potential conflicts of interest

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สาเหตุและทัศนคติของสามีที่ไม่มาตรวจหาภาวะพาหะโรคเลือดจางธาลัสซีเมียเมื่อภรรยามีผลการตรวจคัดกรองผิดปกติ

จุฑาวดี วุฒิวงศ์, ปริศนา พานิชกุล, พีระพรรณ พันธุ์ภักดีคุณ

***ภูมิหลัง**: สาเหตุและทัศนคติของสามีที่ไม่มาตรวจหาภาวะพาหะโรคโลหิตจางธาลัสซีเมีย เมื่อภรรยามีผลการตรวจคัดกรองผิดปกติ*

***วัตถุประสงค์**: เพื่อประเมินทัศนคติของสามีที่ไม่มาตรวจหาภาวะพาหะโรคโลหิตจางธาลัสซีเมีย และสาเหตุที่ไม่ตรวจเลือด*

***รูปแบบงานวิจัย**: เชิงพรรณนา*

***วัสดุและวิธีการ**: ปี พ.ศ. 2550-2551 สามีของหญิงตั้งครรภ์ที่มีผลการตรวจ คัดกรองธาลัสซีเมียผิดปกติจำนวน 100 คน ที่สมัครใจเข้าร่วมในการศึกษาจะกรอกแบบสอบถามที่สร้างขึ้นสำหรับการศึกษานี้ โดยแบบสอบถามแบ่งเป็น 3 ส่วน (1) ข้อมูลทั่วไป (2) ทัศนคติต่อการตรวจหาพาหะโรคโลหิตจางธาลัสซีเมีย ซึ่งจะให้คะแนน 1-5 และ (3) สาเหตุที่ไม่เจาะเลือด*

***ผลการศึกษา**: โดยทั่วไปสามีมีทัศนคติที่ดีต่อการตรวจหาธาลัสซีเมีย (คะแนนเฉลี่ย 3.57, ค่าเบี่ยงเบน 0.38) สำหรับสาเหตุหลักที่ไม่เจาะเลือด เนื่องจากเชื่อว่าทารกในครรภ์ไม่เป็นโรค และความไม่สะดวกในการมาตรวจที่โรงพยาบาล*

***สรุป**: สามีมีทัศนคติที่ดีต่อการตรวจหาภาวะพาหะโรคโลหิตจางธาลัสซีเมีย*